

**Summary of Session 1 AoA Caregiver Listserv:
"Meeting Caregiver Needs: The Right Service at the Right Time"**

January 30 - February 5, 2001

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INTRODUCTION

The first Administration on Aging (AoA) caregiver listserv session, *"Meeting Caregiver Needs: The Right Service at the Right Time,"* was held from January 30, 2001-February 5, 2001. Over 100 state and local representatives from the aging network participated in this new AoA venture to advance information-sharing around critical caregiving topics associated with implementing the National Family Caregiver Support Program (NFCSP). The overall goal of the listserv approach is to move beyond the theoretical constructs of caregiving and toward the practical implications at the operational level for developing the caregiver support programs.

Participants had the opportunity to share program experiences with and pose questions to fellow aging network members and to the research resource for the session, Dr. Rhonda Montgomery (Director of the Gerontology Center at the University of Kansas).

BACKGROUND RESEARCH

The starting point for discussion was a paper authored by Dr. Rhonda Montgomery and Dr. Karl Kosloski (University of Nebraska at Omaha) entitled, "[*Change, Continuity and Diversity Among Caregivers*](#)." The paper highlights the diversity of caregiver experiences and provides a framework for program planners and administrators to effectively target support services. The "marker" framework captures caregiving as a dynamic process and serves as a tool to gauge shifts in caregiving stages and receptivity to services and supports. The seven markers of this caregiving trajectory include: 1) performance of initial caregiving task; 2) self-definition as a caregiver; 3) provision of personal care; 4) seeking out or using assistive services; 5) consideration of institutionalization; 6)

actual nursing home placement; and 7) termination of the caregiver role. The order and timing of markers 2 through 5 are considered defining characteristics of the caregiver experience and that have direct relevance for implementing caregiver support programs. It is important to note that the order and timing of these markers varies depending on the individual and type of caregiver (e.g., spouse versus adult children caregivers). In addition to the type of caregiver, an individual's culture also may play a significant role in the spacing of these markers.

The authors address several implications for program design and delivery:

- First, it is important to **create multiple services that are flexible** to meet the full range of needs of the community being served.
- Second, states should **be cognizant of limited resources and create services for the most prevalent types of caregivers**. The authors suggest assessing the relative prevalence of caregivers who are spouses versus adult children in a catchment area within the context of the "marker" framework since they will likely have different needs for types of educational programs, support groups and respite.
- Third, **effective targeting and marketing of services is necessary in order to reach caregivers at the "servable moment" point**, not after it is too late. In offering respite, for example, only when caregivers reach the point at which they are providing extensive care and have identified themselves as caregivers will they reach the point of receptivity (the "servable moment") to respite programs. Strategies to increase receptivity should be based on the understanding that different types of caregivers arrive at the "servable moment" for different reasons and that caregivers use services only when they perceive the benefits to outweigh the monetary, emotional, or physical costs of using the service.
- Lastly, programs should **create institutional links between service providers** in order to assist the caregiver in identifying services that best meet their

needs at any point in the caregiving trajectory. This will enable a program to contend with the changing nature of the caregiving role.

AGING NETWORK RESPONSES

The paper was well received by both members of the aging network who have had experience in developing caregiver support programs and by those who are just beginning to develop programs. Participants noted the importance of recognizing the diversity among caregivers and their needs as a critical factor in developing and implementing successful caregiver support programs. This diversity includes the gender, relationship (most often spouse or adult child), place of residence (living with or without the care recipient), and ethnicity of caregivers, all of which influence an individual's use of support services. Key questions and comments were raised with respect to the diversity of caregiver experiences and effective timing of services within the following domains:

Flexibility in Program Design and Delivery

State representatives agreed that in order to accommodate caregiver diversity, it is necessary for states to create flexible caregiver support programs. Services should be adaptive and responsive to the differences of the caregivers they are serving. One representative stressed that it is important that State Units on Aging allow Area Agencies on Aging maximum flexibility in program design and implementation, and that in turn, AAAs allow consumers maximum flexibility in the services they choose to use. Similarly, other aging network representatives emphasized the value of creating programs that are designed to meet the needs of their individual community. Thus, local planning and delivery of services is considered a key factor in creating a flexible program.

The Family Caregiver Support Program in Pennsylvania provides up to \$200/month service reimbursement, a \$2,000 "lifetime grant" which may be used for home modification, and a list of approved items and services. This approach allows caregivers to choose services and supports that are most appropriate at any given time. One drawback that was discussed in terms of flexibility with the

PA program is that services are only offered to caregivers that reside in the same household as the care recipient.

Caregiver Needs Assessment

Several state representatives shared their efforts in attempting to address the needs of their communities. In Georgia, a series of focus groups were conducted around the state to learn about the needs and concerns of various types of formal and informal caregivers. The information gathered during this effort included: whether or not the caregiver resides with the care recipient; the relationship of the caregiver to the care recipient; the physical and emotional capabilities of the caregiver to provide the necessary care; and the availability and willingness to provide care. Information is also gathered on what services are currently being provided to meet the caregiver's needs. The goal in collecting this information is to use the findings to expand and enhance the Georgia Caregivers Resource Center. The Executive Office on Aging in Hawaii recently conducted six caregiver focus groups. This effort allowed the state to collect "official data" on caregivers and gain a better understanding of the needs of caregivers in their local community.

Support Groups

Some participants noted that offering a single support group does not address the needs of an entire community. For example, adult children generally attend support groups to gain information about the disease of their care recipient and about services available to them; however, spouses generally attend support groups for emotional support. It was recommended to offer support groups at different times of the day because spouses might prefer morning support groups, while working adult children would most likely prefer evening or online support groups. In addition, representatives noted that because support groups are comprised of individuals interacting with each other, the interpersonal dynamics are just as important to the success of the group as the content of the discussion. In recognizing that caregivers tend to pass through support groups depending on their need at a particular time, it was suggested that programs have a means to

follow-up with past support group members to verify that they are receiving the services and supports they need. Another suggestion was to initiate and encourage “supportive friends” for group members. This option acknowledges that a caregiver’s existing support network of family and friends might not offer all of the types and level of support that a caregiver may need. Establishing a “supportive friend” might allow a caregiver the opportunity to connect with someone else on an informal basis that understands what she or he is enduring. Although some representatives expressed the importance of having more than one support group available to serve a community, representatives from Vermont and Idaho discussed different experiences in providing support groups given the rural nature of their states. They have found that too few caregivers reside in the rural areas to create different groups for the various types of caregivers. In one Vermont community, a support group was formed approximately eighteen months ago in which caregivers meet two hours per month over supper. Group members determine the meeting agenda and a speaker is sometimes invited. Funding, respite, and transportation are provided as needed, and the group pays a facilitator. Communities in Idaho have had similar success which suggests that services must be built around the resources and needs of the local community being served.

Respite

Several participants recommended that the aging network should expand their traditional thinking of what is considered *respite*. Respite has traditionally been thought of as the provision of in-home care and companionship, or the use of institutional services such as adult day care. However, in the broader context, respite is really a relief from caregiving duties. So in thinking outside the box, respite could include a telephone service that calls the care recipient as a reminder to take medication or eat. This service could relieve a working caregiver from the worry that the care recipient will forget, or from the interruption of calling the care recipient themselves. Respite could also include a neighborhood kid reading to the care recipient to allow time for the caregiver to prepare dinner.

This expanded view of respite is another avenue in adopting more flexible services.

Minority Service Use

A common concern of several aging network participants was the low service use by minorities. It was noted that the aging network recognizes the importance of acknowledging and incorporating cultural issues and variations into program design and implementation, but report that this is “easier said than done.” Dr. Montgomery reported that some research has been conducted on minority underutilization of caregiver support services which suggest that the key to resolving this issue is through a concerted effort to design and market a program to the minority group being served. When this concerted effort is made, the minority group is willing to use support services, and although patterns of use are different, as a group, more services are used than in white communities.

Representatives from the state of Washington shared the state’s innovative experiences with increasing minority service use among Alzheimer’s disease caregivers via a 7-year Alzheimer’s Demonstration Project through HRSA/AoA. The premise of the demonstration echoed earlier comments that suggested caregivers only access services if the benefits outweigh the costs (both psychological and financial). The approach was to address the issue of diversity and cultural sensitivity through the establishment of partnerships between AAAs and local ethnic agencies. The partnerships enabled AAAs to develop a relationship with the ethnic community they were attempting to serve, and thereby create more successful outreach and service approaches. Each program offered a variety of core services including outreach, translating and/or creating educational material, community education, case management/caregiver consultation, respite care, and diagnostic/dementia evaluation. However, each project used unique approaches to offering these services based on what they had learned through their relationship with the ethnic community through their partnership. When these approaches were applied, many services often found unsuccessful in minority communities were deemed a success. Indeed, it was

found that caregivers of every culture have similar needs of emotional and practical support, as well as financial assistance. However, the success of this demonstration was not due to the fact that these services were offered, but rather, the success is attributable to **how** the services were offered and **who** offered them. Although this was an Alzheimer's demonstration, the representative felt that many aspects of the project are suitable for other types of caregiver support programs as well. More information on the Washington "partnership approach" can be found on the web at <http://www.lsi.ukans.edu/ger/hrsa/>. In addition, a 20 minute video entitled "*Ethnic Communities and Dementia: Making a Difference*" is available by contacting the Washington State Unit on Aging at 360/902-7797.

Another question posed to Dr. Montgomery was whether service use differed depending on the economic status of the caregiver and care recipient. Dr. Montgomery's research shows that middle-income families used in-home care more than low-income and high-income families. She attributed this to their inability to gain access to institutional care. Whereas high-income families can afford nursing home fees and low-income families often qualify for Medicaid, middle-income families are stuck in a no-man's land: they have too much money to qualify for Medicaid, but they do not have enough money to finance nursing home care on their own.

In regard to introducing program-spending caps, Dr. Montgomery stressed that programs that limit or cap the level of service that providers offer do not serve caregivers or care recipients well. Often, the needs of a family cannot be met because caps are set too low. This encourages the family to move on to the "next service" prematurely, which at times is nursing home placement. Additionally, if a program requires caps, Dr. Montgomery urged to set them relatively high because research indicates that few individuals "overuse services."

Information Dosing/ Point in Time

Another subtopic that received much attention was the importance of reaching caregivers before a point of crisis, such as a hospitalization or a question of

abuse arises. The value of reaching caregivers before it is “too late” is that it avoids premature institutionalization of the care recipient and allows him or her to age in a comfortable surrounding with his or her family or within his or her community. Dr. Montgomery stressed that the most effective means of educating caregivers is through the “dosing of information”. This “dosing” consists of providing the right information at the right time, initiating follow-up with families, and having a link system between service providers. This system stems from Dr. Montgomery’s findings that people retain only the information that they are prepared to grasp. For example, when a caregiver seeks assistance at a point of crisis, it is important to give them information that is relevant to the situation at that particular point in time. Providing too much information would be overwhelming. In addition, if left to family/caregiver initiative, follow-up often takes place too late; however, if a care manager initiates the follow-up, he/she can provide any additional information and/or necessary assistance. Furthermore, a provider link system would educate caregivers that are outgrowing their programs around other services and resources available in their community. This would result in caregivers accessing the services in a more timely manner, before it is “too late.”

The universal question that arose was **how** to reach the caregiver early in the caregiving career. Participants offered two main methods: 1) through a familiar community program or organization, such as a community health program or a church, and 2) through the care recipient’s physician or nurse. Many individuals agreed that involving a physician or nurse seems to be the most viable solution, however, the question of how still remains.

The New Mexico SUA representative addressed her state’s effort to reach caregivers earlier in their caregiver career. She commented that New Mexico has found Internet access to be a tremendous help to caregivers in accessing services, especially among adult children. In addition, New Mexico is planning to implement a demonstration on increasing awareness, information, and assistance through physicians. They have found that many physicians are

unaware of the services available, and thus, do not know how to help caregivers. In collaboration with managed care organizations, the state plans to mail flyers to physicians' offices offering to train office nurses once a month on the services available to caregivers. They hope that educating nurses around availability and accessibility of community services will be an effective means of reaching caregivers at the most appropriate point in the caregiving career.